



10. Daunting but Doable: NKF’s “The Big Ask, The Big Give” program opens the door to living kidney donation.

Every year, April is National Donate Life Month. This is an annual time for increasing awareness of the importance of registering as an organ donor or saving a life by being a living donor. And for kidney transplants, living donation offers the best possible outcomes for recipients. But asking someone to give a kidney can be daunting, and the process can be a challenge. For the next episodes of Kidney Transplant Conversations, we will be hearing from support organizations such as the National Kidney Foundation (NKF), the National Living Donor Assistance Center (NLDAC), and TransplantFirst Academy (TFA) about programs supporting living donation. We’ll also talk with healthcare providers about their professional perspectives, and hear from living donor recipients about their experiences. This week, Jennifer Martin from the National Kidney Foundation tells us all about their program “The Big Ask, The Big Give”, a comprehensive resource which includes webinars and workshops, and makes mentors available by phone. the National Kidney Foundation website link is www.kidney.org/transplantation/livingdonors and you can also call them on 1.855.653.2273.

With series producer and host Rolf Taylor.

Other resources mentioned in this episode include: National Donate Life Month www.donatelife.net/ndlm/; The Johns Hopkins Live Donor Champion Program https://www.hopkinsmedicine.org/transplant/patient_information/live-donor-program.html; National Living Donor Assistance Center www.livingdonorassistance.org/.

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TRANSCRIPT

Rolf Taylor: Welcome back to Kidney Transplant Conversations, our regular podcast featuring diverse perspectives and discussions about kidney transplant and its quality care delivery. I'm Rolf Taylor, your host and series producer. So, this is your resource for hearing firsthand the lift experiences that are generously shared by our diverse guests who are talking about navigating through the world of transplant. Whether you're a professional or one of the 90,000 people waiting for a kidney transplant or the even greater number that has received one, we hope this podcast brings you helpful information and is an inclusive connection to the wide and wonderful kidney transplant community. And we thank the participants and advisors who help create this podcast and our underwriter, Veloxis Pharmaceuticals. All views and opinions expressed in this podcast reflect those of the participants and do not necessarily reflect those of the producers or our underwriters.

April is National Donate Life Month. This is an annual time for increasing awareness of the importance of registering as an organ donor or saving a life while you're still alive by being a living donor. And for kidney transplant, living donation offers the best possible chance of surviving and thriving to someone who needs a kidney because the data tells us that the people who receive a kidney from a living donor have a greater chance of achieving long-term health stability. Of course, giving one of your kidneys to someone is a big deal and so asking someone to help you in that way is also a bit daunting and the whole process raises lots of questions about safety, about finance, about future health, but the medical community and advocacy communities have been united in the belief that living donation is such a win/win/win that some really strong supportive programs are in place to help people through this process, help in a sense of educational support, but also in terms of actual financial support, and many organizations have been working really hard, too, with making policy around things like assisting with the cost of transplant medications over the long-term, which makes sense when you compare the cost of living donation to that of dialysis, which is more expensive in the long-term, but asking someone to give a kidney can be daunting. And so, for the next few episodes of Kidney Transplant Conversations, we'll hear from some support organizations such as the National Kidney Foundation, the National Living Donor Assistance Center and the Transplant First Academy and we'll talk to transplant doctors about their professional perspective, and we'll also hear from living donor recipients and their experiences. So, this week Jennifer Martin from the National Kidney Foundation tells us about their program - The Big Ask, The Big Give, a really, comprehensive resource which you'll find online easily if you Google Big Ask, Big Give.

So, many people won't get a transplant simply because they don't know how to ask and a number of organizations want to show you how, including the National Kidney Foundation whose Vice President for Program Development is with us today. Jennifer Martin, welcome.



Jennifer Martin: Thank you so much. Happy to be here today.

Rolf Taylor: And so, for the next couple of episodes, Kidney Transplant Conversations, we're going to take a deep dive on resources that are available to help people find that kidney transplant, making the ask and, also, helping the donation process move smoothly by removing financial obstacles. So, what are the reasons that people don't ask?

Jennifer Martin: Yes, there are lots of reasons. We hear from a lot of people about their barriers to asking and the common things that we hear a lot about are people just not wanting to ask for help, people being concerned about not wanting people to know, not wanting to be identified as somebody who's sick, people who have concerns about their employer knowing. Many people tell us they don't want to put somebody at risk by having them be a donor. We hear that a lot from people who have children and say, "I don't want my children to donate to me." And then, often, it's just that people don't really know how to communicate their needs. They don't know how to let people know. They want to let people know, but they don't know how to do that and it's a daunting thing to put that out there, so people really need support in doing that.

Rolf Taylor: And, of course, it's so dramatically different from people's usual experience of life. Nothing really prepares us to have to ask other people if they would consider donating a kidney to them.

Jennifer Martin: And we talk a lot about that you could ask. You could ask people to consider donation and some people do that. Other people are more comfortable with kind of a softer ask, making sure that people know that they even have kidney disease to start with. A lot of people we talk to say, "I'd like to find a living donor and get a transplant, but almost nobody in my life even knows that I need one," right, so just letting people know what's going with them and what their need is and how a transplant would help them and that living donation is a possibility and what people would do if they want to consider donation. That could be enough to get people to step forward and say, "You know what? I'll consider this."

Rolf Taylor: My guess would be that you've heard quite a few stories about people who've given a kidney to somebody, and they said to that person, "I wish you'd asked sooner."

Jennifer Martin: Yes, we hear that a lot, that people say, "You know what? If I had just known, I would've donated," or "I would've considered donation. I didn't know," right. So, a big part of what we're doing is not just helping the people with kidney disease to show their story but making sure that people who could donate are aware that that's even an option.

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Rolf Taylor: So, the resources that you've developed to help with this process are called Big Ask, Big Give. So, as we just said, it's a very big ask, but it's also a very big give. How do you come up with that idea? What was the genesis for the program?

Jennifer Martin: Yes, so increasing transplant has always been part of our mission and our goals because we know, as we all know, transplant is the best option for people who have kidney failure and a transplant from a living donor typically does a lot better than a transplant from a deceased donor. So, it's really, important to make sure that people are aware of living donation and aware of their treatment options and that people are aware of living donation. So, we started really in 2017 really reassessing everything that we were doing in transplantation and really assessing, okay, what's the current state of transplant in the U.S. now and what are the current barriers? So, we did a lot of research. We conducted surveys and interviews with kidney patients, with their family members, caregivers, with experts in transplant to say, "What are you seeing or what are you experiencing personally and where we can help?" Right. "What are the gaps? What are the barriers and what are potential solutions?" We really identified from that lots of different barriers. There's a long list of barriers to transplant and so we really at that time looked at, okay, some of the major barriers that we hear about a lot are just awareness. People may not be aware of transplant and their treatment options. They may not have enough knowledge and education about transplant to even pursue that as an option. They may not know how to ask, right, or how to put their story out there. Those are all things that we can help with, so we looked at, what are the resources currently out there? There's some great work done out of Johns Hopkins around their Live Donor Champion Program and so we looked at everything that was out there and really adapted it to the feedback that we were hearing from kidney patients and family members, got input from a lot of different sources and that became the Big Ask, Big Give, so it's really the two sides of the coin. The Big Ask is for people with kidney disease and their family members who may want to seek a transplant, want to find a living donor, but don't know how to share that story, don't how to make that ask, which again could be a direct ask, or it could be something that's more subtle or asking people, help me spread the word. Help me share my story. Help me get the word out there. Then the Big Give side is for people who are thinking about donating a kidney and probably have lots of questions about what that means. What are the potential benefits, the potential risks and how can you help me in making this decision? So, we're not trying to talk people into anything. We're giving people all the tools and resources and education that they need so they can make their own decisions.

Rolf Taylor: So, it's really, the most important thing is facilitating the conversation, facilitating the communication, getting all the information on the table and then people can just make their minds up.

Jennifer Martin: Exactly.

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Rolf Taylor: Do you have people coming who for whatever reason are interested in donating a kidney, but they don't have someone in mind for it? They would just like donate.

Jennifer Martin: Absolutely. Yes, some people are interested in that and that's a beautiful thing that somebody would be willing to consider that for somebody they don't even know. We help anybody who's interested in donating wherever they're at in that process. Some people are ready to go and feel like they've done all the education and research and they're ready to move forward. Others are just kind of thinking about it, right, and they may not be at the point of wanting to contact a transplant center or if they're trying to donate to a specific person, they may not want to let that person know yet. They're just thinking about it. So, we can help people wherever they're at.

Rolf Taylor: So, for Big Ask, Big Give, what are the best ways that people can engage with the program? What resources are available?

Jennifer Martin: Yes, so we have lots of different resources and programs under the Big Ask, The Big Give. It's really designed to be a whole system of support for people, so we're trying to get lots of tools and programs and resources to people so we have a lot of different offerings, and we try to offer them in different formats so that people can get the support that they need in lots of different ways. Where we really started with the Big Ask, Big Give was with a public awareness campaign. So, in 2017, we designed a whole awareness campaign around living donation and transplant really just trying to get stories out there because hearing from somebody who has received a transplant or somebody who's donated a kidney, that has the most impact, hearing people's personal stories. We have videos in English and Spanish. We get articles and placements on TV, newspaper, radio, wherever we can to get those personal stories out there. We partnered with Warner Brothers a couple years ago to get information in a public service announcement before movies, so we're always looking at ways to get those personal stories out there and that awareness campaign is really, ongoing. So, that that's addressing a lot of the barriers to transplant of people just not being aware of it. And then, we added two signature programs, education and training programs, that are offered in English and Spanish, so we have an introductory course on transplant called the *First Steps to Transplant*. So, it's basic education about transplant, about living donation for people who may not know much about it and just want to learn the basics, kind of the one-on-one on transplant, and that's designed to being a really, interactive engaging format. It's not just a lecture, but we're really trying to engage people throughout that and learning and we have those programs in-person. Before COVID, we had those programs in-person and we also offer them as webinars and as on-demand programs. And then, after people go to *First Steps to Transplant*, we have a second course called *Finding a Living Donor*, so this is really where we go in depth on: How are you going to share your story? What would that even look like, right? What would you even say? That's such a big hurdle for people. What would I even say to let people know, right? So, we have lots of examples of how other people with kidney disease or their family members have



shared their need. We actually go through, here's something that somebody posted on social media. Here's something that somebody shared with their place of worship or with a community group that they belong to, and I think that's really the heart of what we do is let's show you really, specific examples and help you come up with an action plan that makes sense for you of where you're going to share. So, from some people, it's, I want to share on social media. That's where I'm comfortable. I use it a lot. And some people, it's community groups. We had one woman who came to a program and afterward she told her book club that she needed a kidney. So, she had been in this book club for decades and nobody even knew that she had kidney disease, right, so that was such a great example of it's not always the person that people think it will be. People think that my donor's probably going to be a close family member of friend, but sometimes it's a little bit more distant connection, right.

Rolf Taylor: And did the book club ask result in a book club give?

Jennifer Martin: It did, yes. So, somebody from this woman's book club donated a kidney to her. And then, we've heard from people, yeah, who shared with the place of worship and somebody that they didn't know or didn't know well decided to donate to them. We've heard of people who had friends of friends of friends donate to them after hearing the story, so sometimes the donors (come) from an unexpected place.

Rolf Taylor: I was thinking, I wonder what happens if you're not really familiar with the webinar process or maybe you don't have a computer or maybe you don't have good bandwidth could someone at say a transplant center or another healthcare center, could they facilitate access?

Jennifer Martin: Yes, absolutely. I mean people could make webinar access available on iPads, for example, in dialysis facilities if they want to offer that education. Post-COVID, we'll start doing in-person programs again that people could access and then we also have other resources under Big Ask, Big Give that are telephone-based as well.

Rolf Taylor: Perfect. So how does the telephone, does that mean they would just call National Kidney Foundation and say, "I want to learn about Big Ask, Big Give," and they're going to get connected to someone who can walk them through it?"

Jennifer Martin: We offer the same kind of education and training in phone-based programs. So, for example, we have a peer mentoring program where we actually train kidney patients to help other kidney patients with whatever it is that they're looking for, so we connect people one-on-one for support. It's all done by phone. It's all done in a confidential format, so people don't exchange their names or their personal phone numbers. And it's just a chance for, for example, people who have kidney disease, maybe they want to talk to a transplant recipient, and they have some questions, or they just want to support, or they want to vent, they can do that in a one-on-one format and all of our mentors are trained by NKF. People have to be selected to be



mentors and go through a pretty extensive training with our social workers on staff who oversee the program, and it just gives people another forum to get the information and support they need. And then, we also connect living donors with people who are thinking about donating a kidney. So, again, whatever they want to talk about, if it's, I have some questions or I want to hear about your personal experience or if people want to really be walked through how to share their story, how to get the word out there. We're actually pilot testing now a more targeted support program where we're actually training kidney patients who received a transplant to really provide intensive support towards, how do you share your story? What do you say? Who are you going to share it with? Let's put together an action plan together. So, that's our Patient Navigator Program and that's more ongoing structured support that takes place over two to three months where people can get all their questions answered and really put together an action plan and implement it.

Rolf Taylor: Fantastic. So, what's the telephone number people should call? Let's mention that.

Jennifer Martin: So, people can contact us tollfree at 855-NKF-CARES. It's 1-855-653-2273 or they can email us at NKFCares@Kidney.org.

Rolf Taylor: And the number one more time.

Jennifer Martin: The number is 855-NKF-CARES, so it's 1-855-653-2273.

Rolf Taylor: Perfect. Wonderful. So, one thing I wanted to mention a little bit today is there are disparities in terms of access to kidney transplants, and disparities might be, we seem to have less access for African Americans, for Hispanics, for Asian communities. How can the Big Ask, Big Give Program help people in a way which is most helpful for their culture?

Jennifer Martin: It's really, about sharing lots of resources and tools with people so they can decide what works for them and what resonates with them. We had a man who came to one of our Big Ask, Big Give programs and at the end of the program, he stood up and he was crying, just bawling, and he said, "I need a kidney transplant. I came here because I want to find a living donor and I'm realizing through this that almost nobody in my life even knows that I have kidney disease or that I need a transplant and that I need to let people know." And he said, "In my culture, men do not ask for help." He said, "I'm Hispanic and in my community, we don't ask for help. I would never ask somebody for help, and I'm realizing through this that I need to ask. I need to put my story out there." And he said, "This has just opened a window of hope for me. I know now how to do that." We work with people from many different cultures who help make sure that our materials and our resources are culturally appropriate, that they're culturally sensitive, that we are giving people examples and tools that will resonate with them and we're always adding to that. It's always a continuous process. We actually went through a process in the past year of really reassessing,



looking at everything that we have again and really reassessing it from an equity lens, so we worked with patients and families and healthcare transplant professionals, as well as experts in healthcare equity to just reassess everything that we're doing and look at, at this point in time, are there changes that we need to make? Are there resources that should be added or modified in some way? So, we did make some changes based on that most recent feedback. So, I think it's just making sure that people have all the options available to them.

Rolf Taylor: And then when it comes to mentorship, presumably you can kind of match people who've had similar experiences, so that they're really going to understand each other.

Jennifer Martin: Exactly, so we have social workers on staff that do a quick assessment of everybody who wants support through the Peer Mentoring Program just to find out more about them and what their specific needs are, so it could be somebody who wants to talk to somebody who had a transplant or it could be somebody who is on a particular type of dialysis and they want to look at other kinds of dialysis or transplant or it could be somebody who says, "You know what? I'm on the younger side." Maybe it's somebody who's 20 years old and on dialysis and they don't know anybody around their age who has had that experience, so they want to talk to somebody who's closer to their age or their situation. So, we can really match people up regardless of whatever it is that they're looking for.

Rolf Taylor: Fantastic. It's really, it's exciting to hear that there are so many resources available, and it sounds like there are more and more different kinds of resources available to overcome different barriers, so hopefully we're going to continue to see more and more people receiving transplants because of that.

Jennifer Martin: Absolutely, so people can contact us at any time. We do have our Help Line, NKF Cares, that is really like a one-stop-shop for people that have questions about anything related to kidneys or kidney disease. So, if people just want to talk to one of our experts on staff about any of this, they can contact NKF Cares. We get about 14,000 inquiries a year in English and Spanish and recently expanded our hours, so we're open from 9AM to 7PM Eastern Time and it's just another way for people to connect with us. We can mail them resources. They can let us know about their particular situation and we can suggest what resources or programs might help them, whether it's from us or from other sources. We want to make sure that people have whatever it is that they need.

Rolf Taylor: Thank you so much for coming on Kidney Transplant Conversations and telling us all about Big Ask, Big Give; and I know that you're going to find a couple of people who've been through the program who can also come on the podcast and share their experiences firsthand, so really looking forward to that. Thank you so much.

Jennifer Martin: Thank you so much for having me.

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Rolf Taylor: And thank you to Jennifer Martin from the National Kidney Foundation for a terrific interview; and you can start to access those resources and sign up for the webinars if you simply Google The Big Ask, The Big Give. The National Kidney Foundation website is www.kidney.org, and you can also simply call them on 1-855-653-2273 and they'll be glad to help.

On our next episode, we'll hear from someone who received a kidney from a living donor after following guidance contained in The Big Ask, The Big Give resources and learn firsthand how The Big Ask, Big Give Program helped them put in place the support they needed and how that all turned out.

Thanks to all our listeners for joining us and thanks again to our underwriters, Veloxis Pharmaceuticals. We look forward to seeing you next time. Bye for now.

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